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DEPARTMENT OF EDUCATION

34 CFR Chapter III

Proposed priority--National Institute on Disability and Rehabilitation Research--Rehabilitation Research and Training Centers

CFDA Number: 84.133B-8.

AGENCY: Office of Special Education and Rehabilitative Services, Department of Education.

ACTION: Proposed priority.

SUMMARY: The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for the Rehabilitation Research and Training Center (RRTC) Program administered by the National Institute on Disability and Rehabilitation Research (NIDRR). Specifically, this notice proposes a priority for an RRTC on Family Support. We take this action to focus research attention on an area of national need. We intend the priority to contribute to improved outcomes in this area for individuals with disabilities and family members who provide assistance to them.

DATES: We must receive your comments on or before [INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

ADDRESSES: Submit your comments through the Federal eRulemaking Portal or via postal mail, commercial delivery, or hand delivery. We will not accept comments submitted by fax or by email or those submitted after the comment period. To ensure that we do not receive duplicate copies, please submit your comments only once. In addition, please include the Docket ID at the top of your comments.

- Federal eRulemaking Portal: Go to www.regulations.gov to submit your comments electronically. Information on using Regulations.gov, including instructions for accessing agency documents, submitting comments, and viewing the docket, is available on the site under "Are you new to the site?"

- Postal Mail, Commercial Delivery, or Hand Delivery: If you mail or deliver your comments about these proposed regulations, address them to Marlene Spencer, U.S. Department of Education, 400 Maryland Avenue, SW., room 5133, Potomac Center Plaza (PCP), Washington, DC 20202-2700.

Privacy Note: The Department's policy is to make all comments received from members of the public available for public viewing in their entirety on the Federal eRulemaking Portal at www.regulations.gov. Therefore, commenters should be careful to include in their comments only information that they wish to make publicly available.

If you use a telecommunications device for the deaf (TDD) or a text telephone (TTY), call the Federal Relay Service (FRS), toll free, at 1-800-877-8339.

SUPPLEMENTARY INFORMATION:

This notice of proposed priority is in concert with NIDRR's currently approved Long-Range Plan (Plan). The Plan, which was published in the Federal Register on April 4, 2013 (78 FR 20299), can be accessed on the Internet at the following site:

www.ed.gov/about/offices/list/ose/nidrr/policy.html.

The Plan identifies a need for research and training in a number of areas, including the needs of families with members with disabilities. To address this need, NIDRR seeks to: (1) improve the quality and utility of disability and rehabilitation research; (2) foster an exchange of research findings, expertise, and other information to advance knowledge and understanding of the

needs of individuals with disabilities and their family members, including those from among traditionally underserved populations; (3) determine effective practices, programs, and policies to improve community living and participation, employment, and health and function outcomes for individuals with disabilities of all ages; (4) identify research gaps and areas for promising research investments; (5) identify and promote effective mechanisms for integrating research and practice; and (6) disseminate research findings to all major stakeholder groups, including individuals with disabilities and their families in formats that are appropriate and meaningful to them.

This notice proposes one priority that NIDRR intends to use for one or more competitions in fiscal year (FY) 2014 and possibly later years. NIDRR is under no obligation to make an award under this priority. The decision to make an award will be based on the quality of applications received and available funding. NIDRR may publish additional priorities, as needed.

Invitation to Comment: We invite you to submit comments regarding this notice. To ensure that your comments have maximum effect in developing the notice of final priority,

we urge you to identify clearly the specific topic within the priority that each comment addresses.

We invite you to assist us in complying with the specific requirements of Executive Orders 12866 and 13563 and their overall requirement of reducing regulatory burden that might result from this proposed priority. Please let us know of any further ways we could reduce potential costs or increase potential benefits while preserving the effective and efficient administration of the program.

During and after the comment period, you may inspect all public comments about this proposed priority by following the instructions found under the "Are you new to the site?" portion of the Federal eRulemaking Portal at www.regulations.gov. Any comments sent to NIDRR via postal mail, commercial deliver, or hand delivery can be viewed in room 5133, 550 12th Street, SW., PCP, Washington, DC, between the hours of 8:30 a.m. and 4:00 p.m., Washington, DC time, Monday through Friday of each week except Federal holidays.

Assistance to Individuals with Disabilities in Reviewing the Rulemaking Record: On request we will provide an appropriate accommodation or auxiliary aid to an individual with a disability who needs assistance to review the

comments or other documents in the public rulemaking record for this notice. If you want to schedule an appointment for this type of accommodation or auxiliary aid, please contact the person listed under FOR FURTHER INFORMATION CONTACT.

Purpose of Program: The purpose of the Disability and Rehabilitation Research Projects and Centers Program is to plan and conduct research, demonstration projects, training, and related activities, including international activities, to develop methods, procedures, and rehabilitation technology that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most severe disabilities, and to improve the effectiveness of services authorized under the Rehabilitation Act of 1973, as amended (Rehabilitation Act).

Rehabilitation Research and Training Centers

The purpose of the RRTCs, which are funded through the Disability and Rehabilitation Research Projects and Centers Program, is to achieve the goals of, and improve the effectiveness of, services authorized under the

Rehabilitation Act through well-designed research, training, technical assistance, and dissemination activities in important topical areas as specified by NIDRR. These activities are designed to benefit rehabilitation service providers, individuals with disabilities, family members, policymakers and other research stakeholders. Additional information on the RRTC program can be found at:

<http://www2.ed.gov/programs/rrtc/index.html#types>

Program Authority: 29 U.S.C. 762(g) and 764(b)(2).

Applicable Program Regulations: 34 CFR part 350.

PROPOSED PRIORITY:

This notice contains one proposed priority.

RRTC on Family Support.

Background:

For the purpose of this notice, "family support" is defined as a range of formal and informal support, assistance or nurturing provided to a family member with a disability by one or more other family members in response to disability-related needs, including needs for self-determination, integration, and inclusion in community life. Family support may include any disability-related support, assistance, or nurturing provided to a child by a

parent, to a parent by a child, by a spouse to a husband or wife, by a sibling to another sibling, or within some other family relationship. "Family caregiver" refers to an individual who provides support, assistance, or nurturing to a family member with a disability. "Family support services" refers to services and cash payments provided to a family caregiver who is providing support, assistance, or nurturing to a family member with disability.

Family support is the predominant source of long-term services and supports for persons with disabilities in the United States (Thompson, 2004). Without the contributions of family members, the public costs and demand for paid personal assistance would increase dramatically and become unsustainable. Estimates of the annual cost of services provided by family members to individuals with disabilities range from about \$335 billion (Feinberg, Reinhart, Houser & Choula, 2011), to \$450 billion (White-Means & Dong, 2012), or roughly three times the total State and Federal Medicaid expenditures for compensated long-term services and supports (Eiken, et al., 2013).

In addition to the value of the uncompensated hours of family direct support, families routinely incur substantial out-of-pocket expenses associated with a family member's

disability (Lewis & Johnson, 2005; Mitra et al., 2009). Furthermore, families that include at least one individual with a disability often experience substantial economic and career losses (Anderson, Larson, Lakin & Kwak, 2002; Parish, Seltzer, Greenberg & Floyd 2004; Stabile & Allin, 2012). Family caregivers experience stresses other than economic, including psychological (Traute & Heibert-Murphy, 2002), social (Baxter, Cummins & Yiolitis (2000), and health (Gallagher & Whitely, 2012) stresses.

Family support is essential to the viability of the U.S. system of long-term services and supports for persons with disabilities. Family support services may include information services, person and family-centered planning, counseling, assistive devices, home modifications, respite care, training, personal care attendant and homemaker recruitment and training, meal services, cash assistance, and other supports as needed.

In March 2013, the U.S. Department of Health and Human Services (HHS) launched a new Community Living Council in support of the "Secretary's Strategic Initiative to Promote Community Living for Older Adults and People with Disabilities" (Initiative) (U.S. Department of Health and Human Services, 2013). The Initiative engages multiple HHS

agencies and partners from other Departments to assist States in making their systems of Long-Term Services and Supports (LTSS) more community-based, consumer-directed, and outcome-focused. The Initiative includes major efforts to provide factual, accessible, and easily understood information to individuals with disabilities and their families. The intent of the Initiative corresponds directly with NIDRR's mission to generate new knowledge and promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community.

To further the central goals of the Initiative, NIDRR is partnering with the Administration for Community Living (ACL) in HHS to create a national RRTC on Family Support. ACL will support the engagement of its 356 Aging and Disability Resource Centers to serve as a conduit for information generated by the RRTC. The purpose of this RRTC will be to engage in research, data analysis, knowledge translation, and development and dissemination of informational products to improve supports and services for individuals who provide assistance to their family members with disabilities.

References:

Anderson, L., Larson, S., Lakin, K.C., & Kwak, N. (2002). Children with disabilities: Social roles and family impacts in the NHIS-D. DD Data Brief, 4(1).

Baxter, C., Cummins, R., & Yiolitis, L. (2000). Parental stress attribute to family members with and without disability. Journal of Intellectual and Developmental Disability, 25(2), 105-118.

Feinberg, L., Reinhart, S., Houser, A., & Choula, R. (2011). Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. Washington, DC: AARP Policy Institute.

Gallagher, S., & Whiteley, J. (2012). Social support is associated with blood pressure responses in parents caring for children with developmental disabilities. Research in Developmental Disabilities, 33(6), 2099-2105.

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Lewis, D., & Johnson, D. (2005). Costs of family care for individuals with disabilities. In R. Stancliffe & K. Lakin (Eds.), Costs and outcomes of community services for people

with intellectual disabilities (pp. 63-89). Baltimore:
Paul H. Brookes.

Mitra, S., Findley, P., & Sambamoorthi, U. (2009). Health
care expenses of living with a disability: Total
expenditures, out-of-pocket expenses, and burden. *Archives
of Physical Medicine and Rehabilitation*, 90, 1532-1540.

Parish, S., Seltzer, M., Greenberg, J., & Floyd, F. (2004).
Economic implications of caregiving at midlife: Comparing
parents with and without children with developmental
disabilities. *Mental Retardation*, 42(6), 413-426.

Stabile, M., & Allin, S. (2012). The economic costs of
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96.

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caregivers. Georgetown University, Health Policy
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family caregiving: Time and motion survey estimates.
Consumer Interests Annual, 58(1), 1-6.

Proposed Priority:

The Assistant Secretary for Special Education and Rehabilitative Services proposes a priority for an RRTC on Family Support. The RRTC's work is intended to inform the design, implementation, and continuous improvement of Federal and State policies and programs related to assisting families in support, assistance, and nurturing of family members with disabilities. The RRTC would also identify and develop information for individuals with disabilities and their family members to guide their informed choice of community and family-based service and support options that best meet their needs.

The RRTC must be designed to contribute to better understanding of the phenomenon of family support; to improved community living and participation, health and function, and employment outcomes of individuals with disabilities supported by family members; and to effective support of family caregivers by--

(a) Developing and implementing a project research plan to identify the key elements of family support and family support programs and policy. This plan, once implemented by the grantee, must contribute to identification or development of relevant and high quality data and information that will serve as an empirical

foundation for improving assistance to families in support roles and to family support policies and programs. This task includes:

- (i) Developing a conceptual framework for research on family support that includes both individual and societal level characteristics that influence provision of family support, considering existing knowledge about family support barriers in other populations.

- (ii) Developing and prioritizing a list of research questions and evaluation topics that, when addressed, would lead to research-based information that can be used to improve family support policies, practices, programs, communications, and outcomes.

- (iii) Working with NIDRR and ACL to identify relevant data sets and informational resources that can be analyzed to address the questions and topics in the research plan; and

- (iv) Working with NIDRR and ACL to identify gaps in data and information resources that are available to address the questions and topics in the research plan and to identify strategies to fill those gaps;

- (b) Conducting research and research syntheses to describe the nature and extent of support that is being

provided to individuals with disabilities by family members, and the extent to which the family caregivers themselves receive assistance in the form of education/training, counseling/psychosocial support, personal care, homemaker services, respite care and other relevant supports, as well as the amounts of assistance received and the private and public sources of payment for such assistance;

(c) Conducting research and research syntheses to identify and evaluate promising practices that States have used and could be adopted in other States to improve long-term services and supports for families of individuals with disabilities. This task includes--

(i) Identifying components of well-designed, effective State or local family support programs; and

(ii) Identifying and assessing methods for monitoring, tracking and evaluating States' approaches to supporting families, which may include, but are not limited to, methods for monitoring the experiences of individuals and costs for recipients of family support services within broader existing LTSS evaluation programs, such as the National Core Indicators or Participant Experience Survey; methods for understanding, monitoring and responding to the

unique needs of individual families, including the family members with and without disabilities; and methods for evaluating the outcomes for individuals and families receiving family support services;

(d) Identifying and involving key stakeholders in the research and research planning activities conducted under paragraphs (a), (b) and (c) to maximize the relevance and usefulness of the research products being developed.

Stakeholders must include, but are not limited to, individuals with disabilities and their families (including parents, siblings, and sons/daughters); national, State and local-level policymakers; service providers; and relevant researchers in the field of disability and rehabilitation research;

(e) Identifying, evaluating, and disseminating accessible information at the national, State, service provider, and individual levels on topics of importance to sustaining and developing appropriate and effective family support services, practices, policies, and programs. These topics include, but are not limited to: usefulness and effectiveness of current family support resources for families of differing circumstances; the roles of, and impact upon, families in the transitions from fee-for-

service to integrated/managed long-term service and support systems; the roles and responsibilities of individuals with disabilities and their family members in the transition from agency-directed to consumer-directed services; best practices in supporting families both within and outside of disability services; accessing and coordinating community supports; the role of family-to-family and peer-to-peer support systems and other social networks; and other topics to be determined in collaboration with key stakeholders, NIDRR, and ACL representatives;

(f) Establishing a network of technical assistance providers and advocacy entities to assist in synthesizing and disseminating information related to implementing high quality family support policies, programs and practices for individuals with disabilities. Network members should include, but are not limited to: the Aging and Disability Resource Centers, the State Councils on Developmental Disabilities; Parent Training and Information Centers; Protection and Advocacy Client Assistance Programs; Centers for Independent Living, and private sector organizations that are recognized as national leaders in promoting family support policies, programs and research; and

(g) Serving as a national resource center related to family support by--

(i) Providing information and technical assistance to individuals with disabilities, family members, service providers, policymakers and other key stakeholders;

(ii) Providing training to facilitate understanding of the effective use of private and public options for the provision of supports to families, including training at the graduate, pre-service, and in-service levels, and to individuals with disabilities, families, and rehabilitation and other service providers. This training may be provided through conferences, workshops, public education programs, in-service training programs, and similar activities; and

(iii) Collaborating as appropriate with NIDRR's RRTC on Community Living Policy.

Types of Priorities:

When inviting applications for a competition using one or more priorities, we designate the type of each priority as absolute, competitive preference, or invitational through a notice in the Federal Register. The effect of each type of priority follows:

Absolute priority: Under an absolute priority, we consider only applications that meet the priority (34 CFR 75.105(c)(3)).

Competitive preference priority: Under a competitive preference priority, we give competitive preference to an application by (1) awarding additional points, depending on the extent to which the application meets the priority (34 CFR 75.105(c)(2)(i)); or (2) selecting an application that meets the priority over an application of comparable merit that does not meet the priority (34 CFR 75.105(c)(2)(ii)).

Invitational priority: Under an invitational priority, we are particularly interested in applications that meet the priority. However, we do not give an application that meets the priority a preference over other applications (34 CFR 75.105(c)(1)).

Final Priority:

We will announce the final priority in a notice in the Federal Register. We will determine the final priority after considering responses to this notice and other information available to the Department. This notice does not preclude us from proposing additional priorities, requirements, definitions, or selection criteria, subject to meeting applicable rulemaking requirements.

Note: This notice does not solicit applications. In any year in which we choose to use this priority, we invite applications through a notice in the Federal Register.

Executive Orders 12866 and 13563

Regulatory Impact Analysis

Under Executive Order 12866, the Secretary must determine whether this regulatory action is "significant" and, therefore, subject to the requirements of the Executive order and subject to review by the Office of Management and Budget (OMB). Section 3(f) of Executive Order 12866 defines a "significant regulatory action" as an action likely to result in a rule that may--

(1) Have an annual effect on the economy of \$100 million or more, or adversely affect a sector of the economy, productivity, competition, jobs, the environment, public health or safety, or State, local, or tribal governments or communities in a material way (also referred to as an "economically significant" rule);

(2) Create serious inconsistency or otherwise interfere with an action taken or planned by another agency;

(3) Materially alter the budgetary impacts of entitlement grants, user fees, or loan programs or the rights and obligations of recipients thereof; or

(4) Raise novel legal or policy issues arising out of legal mandates, the President's priorities, or the principles stated in the Executive order.

This proposed regulatory action is not a significant regulatory action subject to review by OMB under section 3(f) of Executive Order 12866.

We have also reviewed this regulatory action under Executive Order 13563, which supplements and explicitly reaffirms the principles, structures, and definitions governing regulatory review established in Executive Order 12866. To the extent permitted by law, Executive Order 13563 requires that an agency--

(1) Propose or adopt regulations only upon a reasoned determination that their benefits justify their costs (recognizing that some benefits and costs are difficult to quantify);

(2) Tailor its regulations to impose the least burden on society, consistent with obtaining regulatory objectives and taking into account--among other things and to the extent practicable--the costs of cumulative regulations;

(3) In choosing among alternative regulatory approaches, select those approaches that maximize net benefits (including potential economic, environmental, public health and safety, and other advantages; distributive impacts; and equity);

(4) To the extent feasible, specify performance objectives, rather than the behavior or manner of compliance a regulated entity must adopt; and

(5) Identify and assess available alternatives to direct regulation, including economic incentives--such as user fees or marketable permits--to encourage the desired behavior, or provide information that enables the public to make choices.

Executive Order 13563 also requires an agency "to use the best available techniques to quantify anticipated present and future benefits and costs as accurately as possible." The Office of Information and Regulatory Affairs of OMB has emphasized that these techniques may include "identifying changing future compliance costs that might result from technological innovation or anticipated behavioral changes."

We are issuing this proposed priority only upon a reasoned determination that its benefits would justify its

costs. In choosing among alternative regulatory approaches, we selected those approaches that would maximize net benefits. Based on the analysis that follows, the Department believes that this proposed priority is consistent with the principles in Executive Order 13563.

We also have determined that this regulatory action would not unduly interfere with State, local, and tribal governments in the exercise of their governmental functions.

In accordance with both Executive orders, the Department has assessed the potential costs and benefits, both quantitative and qualitative, of this regulatory action. The potential costs are those resulting from statutory requirements and those we have determined as necessary for administering the Department's programs and activities.

The benefits of the Disability and Rehabilitation Research Projects and Centers Program have been well established over the years. Projects similar to one envisioned by the proposed priority have been completed successfully, and the proposed priority would generate new knowledge through research. The new RRTC would generate, disseminate, and promote the use of new information that

would improve outcomes for individuals with disabilities in the areas of community living and participation, employment, and health and function.

Intergovernmental Review: This program is not subject to Executive Order 12372 and the regulations in 34 CFR part 79.

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Dated: March 18, 2014

Michael K. Yudin,
Acting Assistant
Secretary for
Special Education and
Rehabilitative Services.

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